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TITLE: National Native American Breast Cancer Survivor's Network

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CONTRACTING ORGANIZATION: National Indian Health Board
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| 13. ABSTRACT (Maximum 200 Words) The Native American Breast Cancer Survivors' Support Network (DAMD17-99-1-9310) is a three year-project supported by the Department of Defense. This project is being conducted by Native American Cancer Research in collaboration and partnership with the National Indian Health Board. The purpose of this project is to improve the survival from breast cancer and quality of life after being diagnosed with breast cancer for both the patient and loved ones of the cancer patient. The study objectives follow: (a) using key and well recognized Native American cancer leaders from geographically diverse regions of the country, identify and recruit Native American breast cancer patients into the survivors' network and database; and (b) refine, and evaluate the survivor's database to determine patterns of disease and patterns of care experienced by Native American breast cancer survivors. The intended population is Native American breast cancer patients, both genders, ages 20 and older, living anywhere on the North American continent. Preliminary findings include documentation that Native breast cancer survivors are not receiving quality care, less than one-third have access to insurance (and thus access to improved quality of care) and standard protocols used with other survivors are ineffective with Native cancer survivors. | | | | |
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INTRODUCTION

The Native American Breast Cancer Survivors' Support Network (DAMD17-99-1-9310) is a three year-project supported by the Department of Defense from September 1999 through September 2002. *** Due to circumstances beyond our control (explained later), the project was not initiated until March 2000 (thus our project dates should be March 2000 through February 2003).* This project is being conducted by Native American Cancer Research (NACR) in collaboration and partnership with the National Indian Health Board, the Native CIRCLE, and the Center for Healthy Aging. [NACR is our newly established non-profit corporation that the project now runs through. This non-profit had yet to be established at time of application or award date]. The project addresses various support issues for those dealing with breast cancer and to learn more about how cancer is affecting Native communities. The purpose of this project is to improve the survival from breast cancer and quality of life after being diagnosed with breast cancer for both the patient and loved ones of the cancer patient. The study objectives follow: (a) Using key and well recognized Native American cancer leaders from geographically diverse regions of the country, identify and recruit Native American breast cancer patients into the survivors' network and database; and (b) Refine, and evaluate the survivors' database to determine patterns of disease and patterns of care experienced by Native American breast cancer survivors. The intended population is Native American breast cancer patients, both genders, ages 20 and older, living anywhere on the North American continent. As of September 2000, there are twelve Native American Survivor Advocates, of whom half are cancer survivors and eleven are American Indian or Alaska Native. The Survivor Advocates primarily reside in Native communities and Villages in diverse geographic regions of the North American continent (e.g., Alaska, California, Oklahoma, Arizona, New Mexico, Minnesota, Wisconsin, Colorado, Oregon, Wisconsin, and New York) and work from their homes.

BODY

The referral by leaders in American Indian and Alaska Native organizations to the Survivors' Network is becoming more effective every month. The Native CIRCLE remains one of the most active referral sites. Arizona Cancer Center has also begun to actively refer patients. The Internet has also been another good source from people finding our Web Page and contacting us. The National Susan G. Komen Breast Cancer Foundation has a Hot Line that also refers women to our program. The P.I. does many public speaking engagements throughout American Indian and Alaska Native communities and referrals are also generated from these presentations.

The patterns of cancer will require many more patient surveys to be collected before a "true" pattern is identified. The data presented in this report includes data collected from Komen supported efforts of this Survivors' Network and from data restricted by DoD protocols. The Survivor Advocates are effective in collecting the data and establishing rapport with the patients. At the present time, all components of the "Network" appear to be working, with the exception of the long distance phone card incentives. The phone company with whom we had established a good working relationship was taken over by another company and we have not had access to our Program-specific cards for a year. We are now purchasing over-the-counter Phone Cards from Costco and Target and have requests for donations into both organizations.

Several tasks have taken longer than anticipated. Some unusual problems and challenges have also been encountered. Since these are closely integrated within the functioning of the Network and modifications

to address the problems as well as findings from the network, these are summarized in the following section, "Key Research Accomplishments".

KEY RESEARCH ACCOMPLISHMENTS
A 6-month Report (March 2000 through September 2000)

Approved Statement of Work:

Task 1: Refine the plan for active recruitment into the survivors' database for all participants of the Social Network, Months 1-3

- a. review pilot data from on-going Komen/Breast Ca Fund survivors' network project
- b. modify intake instrument based on Advisory Board's recommendation
- c. Modify survivor's computer intake and follow-up database program to be consistent with revised intake instrument
- d. Co-investigators train data manager
- e. Modify consent form based on Advisory Boards recommendation
- f. Submit application to COMIRB
- g. Train site coordinators on confidentiality and intake data protocols.

Progress to Date: All of the above have been accomplished.

Task 2. Collection of Survivors' Intake data, Months 4-33

- a. after receiving the breast cancer survivor referral, the site coordinators and PI contact the patient and collect informed consent and intake data. 30-minute phone cards will be mailed to those Native Americans who do not have phones. Estimate 100 survivors in Year 1, 200 in Years 2 and 3.

**Using the limitations of the DoD "witness" during the informed consent, during the first 6 months, 22 intakes have been collected.
Phone cards have not been available.**

- b. Intake forms are submitted to Rick Clark of Morning Dew Productions for data loading and correction. Estimate 100 intakes in Year 1, 200 in years 2 and 3.

Intakes loaded by Rick.

- c. Dr. Dignan verifies accuracy of data entry by randomly selecting 10% sample of intake forms and performing an independent data load. Inconsistencies will be discussed and re-training will occur. If deemed necessary.

Dr. Dignan will verify data once 50 intakes have been loaded into the computer program.

- d. Link Native Americans to related on-going projects – Native American breast cancer support resources and services (i.e. link with a telephone support Sister, the six culturally relevant support booklets, videos, pre-paid long-distance phone cards).

All support materials mailed to Native patient participants

Task 3. Collection of medical records and verification of self-reported data, Months 4-33.

- a. Review and modify, if necessary, the medical record abstract protocols used for Alaska Native Tumor Registry

The Alaska Native Tumor Registry protocols were reviewed and found to be insufficient and included excessive errors, particularly tracking from time of diagnosis to treatment and side effects of treatment / disease.

- b. For those survivors who agreed to have copies of medical records sent to the survivors' Network, the site coordinators will request copies of medical records. A \$15 fee will be sent to the medical provider's office to cover photocopying expenses and staff time to copy files. Estimate 75 survivors in year 1(i.e, delay of receipt), 175+ in Year 2, and 225+ in year 3.

The medical records protocols continue to be refined. Anticipate requests of medical records to begin November 2000.

- c. Pull relevant data (e.g. staging, histologic grade, recommendations for treatment, recommended site follow-up care) from medical records and load into survivors database.

Collection of medical records to date indicate significant errors, missing information, and similar problems / errors.

Task 4. Refine database, Month 9-33

- a. Based on preliminary data runs, review data at six months after data collection was initiated to determine database problems while the number of Native Americans in the database is still small enough to be manageable. Month 9
- b. Based on PI and Co-investigators recommendations, determine which cross tables should be run and when they should be run.
- c. Produce data run every six months to review accuracy data and preliminary indications of trends that should be closely documented.

Task 5. Evaluation of the Database, Months 24-36

- a. PI and CO-Investigators produce cross tabulations and run preliminary statistical analysis. Advisory Board review and makes recommendations for additional statistical calculations.
- b. Preliminary data summarized and included in NIHB quarterly newsletter. Press releases of other data, as well as clarification that it is only preliminary, be disseminated to tribal newspapers and magazines.
- c. Preparation and submission of (1) papers for Tribal Communities; Native (lay population and providers) meetings (eg. Association of American Indian Physicians, National Indian Health Board Annual Consumers Meeting, Native Wellness and Women Conference,

Society for the Advancement of Chicanos and Native Americans in Sciences, American Indian Science and Engineering Society, IHS Annual Research Conference; (3) professional meetings for presentations (e.g. American Public Health Association; ASPO, Endocrine Society Annual Meeting); and (4) professional peer-reviewed journals and publications (e.d. Cancer, Epidemiology).

d. Submission of final report to DoD.

Task 4, 5, 6: we are only in month 6 of the DoD project.

WHAT WE HAVE LEARNED ABOUT ... WHAT IS *REALLY* HAPPENING TO NATIVE BREAST CANCER PATIENTS

- There are approximately 100 Native American breast cancer survivors enrolled in the Survivors' Network, of which there are multiple "categories" and "arms". The DoD arm comprises approximately twenty patients. Recruitment into the Survivor Network for the DoD arm began May 2000. Challenges to this arm are (1) the "witness" mandate from DoD to be implemented during the informed consent process; and (2) patient distrust of the Department of Defense. Both are explained later in the report.
- Second opinion for their diagnosis = only for those with insurance (< of the Network members). None who utilize IHS CHS have had access to a second opinion.
- The interval between the time of diagnosis (biopsy) to initiation of treatment = 3-6 months average. For American Indian and Alaska Native women on Medicare, the average interval is six months.
- Contracted Health Services and "fiscal year" referral issues. Women in selected regions of the country who had an abnormal mammogram during the latter part (July, August, September) of the federal fiscal year are at risk for not being referred for appropriate follow-up care (e.g., diagnostic mammogram, biopsy). Such referrals occurred after October 1 (beginning of new fiscal year). The patients believe that CHS was out of money and thus they were not referred until monies were available.
- National Indian Health Board has been attempting to hire the staff member who will assist with collection of patients cancer-related medical records (for verification of staging, histologic grade, tumor size, metastasises). Since actual recruitment into the DoD arm of the Survivors' Network began in May 2000 and about twenty people have been enrolled so far, this has not been a problem. But medical records do need to be requested soon.
- Quality of care. NACR bases "quality of care" on the NCI PDQ. For those patients who have medical insurance (less than 1/3 of the Komen / DoD patients collectively), they have been able to access quality care. Only those patients with medical insurance have been able to choose between lumpectomy with radiation versus mastectomy. All but one IHS CHS patients have had mastectomy. Only women who have insurance have been offered tamoxifen.
- Three Alaska Native women have died of breast cancer during 2000.

- Only one woman had access to Sentinel node surgery. None of the women have been enrolled in clinical trials and only two recalled any discussion of clinical trials by their health care facility staff.

WHAT HAVE WE LEARNED ABOUT DATA COLLECTION?

- The Survivor Advocates cannot conduct data collection (survey) on newly diagnosed Native patient. American Indian and Alaska Native patients experience too many challenges accessing treatment to be willing to participate in an interview; the average time from diagnosis (i.e., biopsy) to initiation of treatment is 3-6 months; some “delays” due to Indian Health Service (IHS) contracted health services (CHS) “priority lists” and insufficient funds latter portion of the federal fiscal year; some “delays” are due to arranging for family care while patient is away for treatment (e.g., Treatment provided through tribal programs and IHS CHS requires that the patient travel to a facility such as UCLA, Fred Hutchinson Cancer Research Center, Alaska Native Medical Center. Newly diagnosed patients need immediate support services.
- NACR cannot use existing survey forms. Standardized survivor intake forms were presented (actually prior to DoD support) and none were acceptable. Self-administration was inappropriate and resulted in forms not returned, missing data and inaccurate data. Telephone interviews were subsequently used. Most effective administration methodology is face-to-face, but since the survivors and Survivor Advocates are located in geographically diverse areas, telephone interviews is the methodology used.

Survey instruments for the “Contributors to Native Knowledge” have been modified nineteen times.

- Elder Native cancer patients do not effectively use common “pain” forms / scales. This concept was pretested through funding other than DoD, but relates to data collection within the DoD project. “Pain” and similar cancer patient forms are based on linear scales (e.g., thermometer to measure severity of pain; Likert scales). Although these formats may be effective in younger American Indian and Alaska Native cancer patients, elders did not understand the assessments. Common responses were “4” or “7” for almost every item. Through focus group meetings with inter-tribal elder cancer survivors, it was learned that elders didn’t understand what was being asked and were responding with a favorite number or sacred number (e.g., “4”). Appropriate pain response scales have yet to be developed for elder American Indian and Alaska Native cancer patients.

WHAT HAVE WE LEARNED ABOUT TRAINING THE “SURVIVOR ADVOCATES”?

- Ten Survivor Advocates took part in a 2-day training held in Denver during February 2000. An additional day of training was needed for those who had never used a computer before. Telephone support was provided by Rick Clark to help staff improve competence.
- The Survivor Advocates all needed computers and subsequently computer training. Native American Cancer Initiatives purchased computers independent of DoD funding since this was an unexpected cost that had not been included within the budget estimate. Electronic mail is a functional way to communicate with staff. The goal is to have Private Internet Chat Sessions with Survivor Advocates once their computer competence improves.

- Access to the Internet: Access to the Internet is questionable. Some of the Survivor Advocates have experienced several challenges accessing the Internet. Since some live on Reservations (e.g., Gila River) or rural communities (e.g., Kotzebue, Alaska), there was no local Internet server. Long distance and toll charges are necessary to connect from their local settings and each has had problems with being cut off the Internet.
- Monthly conference calls: The Survivor Advocates began having monthly conference calls in May 2000. These greatly assisted in improving collection of consent forms, survey administration, processing of paperwork to and from the Native American Cancer Research offices.
- Data Collection Procedures: Takes about 5 times before *really* comfortable with data collection procedures. The consent forms and data collections are very complex and require multiple practice implementations (i.e., over the phone with other Survivor Advocates who role-play for one another). The first data collection is typically preceded and followed by a call with the Survivors' Network Coordinator (Alisa Gilbert). The Administrative Coordinator (Judy Hariton) of NACR also interacts with each Survivor Advocate on tracking the collection and submission of all appropriate forms. Judy also mails all materials to study participants and tracks the referral dates and receipt dates of all documentation.
- The Survivor Advocates required a lot of support to conduct the initial call to patients, particularly for those who were cancer survivors themselves. The range of time from the training to initiation of data collection phone calls was three to six months.
- Survivor Advocates continue to need and want regular communication, interaction and support from one another. Alisa Gilbert, Network Coordinator, communicates with each Advocate at least every other week via phone and weekly by e-mail.

WHAT HAVE WE LEARNED *OVERALL* ABOUT THE PROCESS / PROGRAM?

- Having long distance phone cards are essential for the patients. The incentive for completing the survivor intake survey is receipt of a 100-minute long distance calling card. Concurrently, NACR assigns the patient to another Native American breast cancer survivor for social and emotional support. This contact is very important. Thus far, over half of the women in the entire Network and almost all of those within the DoD subset of the Network have stated that there is no local support available for them. Of those who attended survivor support groups, almost all dropped out due to cultural irrelevance. The telephone "Sister" or "Brother" provides such support (e.g., people talk, pray, cry, laugh, and sing together over the phone).
- Need full-time coordinator. Alisa is part-time and her skills are needed for more than is currently allocated. In addition to her phone support for the Survivor Advocates and patients, we need her to be able to travel to Native gatherings to describe how the Network can be of assistance to the cancer patient.
- Cannot rely on local support groups. The breast cancer patients have needed to address cultural perceptions and issues related to their cancer diagnosis. Non-natives do not understand these

concepts and subsequently, the Native patients frequently have difficulty relating to the other cancer patients and “hold fears inside”.

- Must have the “Service Users” category. Through the Komen Foundation and California Community Foundation Support, a “Service Users” participation category has been implemented. This “category” is essential to providing direct support (culturally specific breast survivors print and video information and resources; telephone support). Most participants of the “Service Users” evolve to “Contributor to Native Knowledge” (i.e., the DoD and Komen supported “arm” of the Survivors’ Network) within nine months of cancer diagnosis.
- This DoD mandate for a “witness” implies that the Survivor Advocates have done something inappropriate and thus now “can’t” be trusted to follow the protocols. This “witness” increased distrust by the patient. Since it is very difficult to establish and maintain trust during any research project, the “witness” raises suspicions within a population that is already distrustful of “research” of any kind.

“Witness” aspect of informed consent is inappropriate ... from the perspective of the patient

- ❖ Implies access to more than one phone? Pay phone?
- ❖ Privacy of someone else in home at the time of the call
- ❖ Privacy — other families *may not know diagnosis* ...this process violates the patient’s privacy and confidentiality
- ❖ “Witness” aspect of informed consent is inappropriate ... from the perspective of the Survivor Advocate
- ❖ Implies access to more than one phone?
- ❖ Implies Survivor Advocates have done something wrong to have to have a witness on line
- ❖ TRUST is questioned
... by a population that is *already* distrustful of any data collection efforts
- Distrust of the Department of Defense. To date NACR has received refusals from five patients to provide personal information, including the survivor intake, because of distrust of the DoD. In general American Indians and Alaska Natives have many reasons to not trust research conducted by anyone from outside the community. However, the five refusals to participate have been from Indian lawyers and people who were formerly in the Armed Services. The latter group has stated independent of one another that they have been told by the Army or other respective agency, that they are not to take part in any health research. That such disclosing of information can violate their discharge “agreements” with the Armed Services. Two have expressed concern that the DoD will misuse private information and that their children can be affected. Some of these comments clearly relate to concerns of genetic testing that can result in loss of employment or insurance coverage for

the patient and the offspring. The Survivor Advocates have clarified that no specimens are ever collected as part of the Survivors' Network and attempted to clarify other misinformation. To date none of the five have been enrolled.

WHAT HAS TAKEN MORE TIME THAN ANTICIPATED?

- The University of Colorado Multiple Institutional Review Board (COMIRB) was placed on suspension by NIH's OPRR and the USDA for their drug clinical trial protocols being out of compliance with Federal guidelines. All research projects that utilized the COMIRB were mandated to cease all research until the University was able to correct its procedures. All projects had to resubmit all documentation related to the Protection of Human Subjects and the COMIRB began with their drug studies (which were the projects out of compliance) and gradually worked through all grants. Native American Cancer Research is a community-based organization that used the COMIRB for all project assurances. Although we had obtained IRB approval from the University May 1999, we too had to resubmit all paperwork. The University's IRB reviewed and approved our application (COMIRB Protocol 98-225) March 6, 2000. Thus the DoD project did not officially begin until March 2000. We could not "recruit" from September 1999 to March 2000, and determined that we should not officially "start" this grant project until the COMIRB suspension and subsequent re-approval of our project had been obtained.
- Getting the Survivor Advocate staff "up-to-speed" following the training. The initial training needed at least three full days rather than two. A great deal of telephone support was necessary to help the Advocates feel comfortable with the data collection protocols and with the use of their new computers.
- Several of the patients have had serious questions about the quality of care they have been receiving. Both Alisa and the P.I. have followed up on these queries. In addition, both Alisa and the P.I. have sought additional help / services / support from their respective local areas. Medical queries have been referred to our oncologists as needed. Other common questions include, but are not limited to service system, quality of care tamoxifen and other aspects of hormonal therapy, cultural issues, and traditional Indian medicine.
- The Survivor survey intake computer program has required changes for every change in the instrument. This has taken time both to rewrite the program and to recode previously loaded intakes.
- Survivor Advocates have requested that they mail the respective packets to the patients and document when and how the mailings have been completed. With the exception of the Network Coordinator, Alisa Gilbert, none have managed these tasks at an acceptable level. Subsequently, NACR Administrative Coordinator, Judy Hariton, tracks all members and mailing packet(s) dates, etc.

REPORTABLE OUTCOMES

- Since we are only six months into the DoD arm of the "Network", we have not submitted any manuscripts. However, a segment of an article to *Oncology Nursing Seminars* does include selected findings. This manuscript will be submitted September 29, 2000.
- We also plan to submit a preliminary findings article to *Cancer Practice* during the winter 2001.

- Patents and informatics are not appropriate to this study.

CONCLUSIONS

Although the process for this Network is quite unique from support programs implemented within other cultures, this program appears that it will be successful in creating a survivors database and being able to document patterns of cancer care among Native American breast cancer patients.

REFERENCES

None used for this report; not applicable

APPENDICES

Not applicable at this time.

FINAL REPORTS

Meeting Abstracts: The Native American Breast Cancer Survivors' Support Network has been presented at the following meetings:

1999 Presentations: (Chronological Order for which information about the Network was included or highlighted)

- *"Native American Breast Cancer Support--Training Outreach Workers"* at Rincon Rancheria, Pauma, CA. January 5-6, 1999.
- *"Native American Breast Cancer Survivors' Support Network"* at National Susan G. Komen Breast Cancer Foundation Affiliate Meeting in Dallas, TX on February 5, 1999.
- Poster on, *"Native American Breast Cancer Survivors' Support Network."* at National Cancer Institute Office of Cancer Survivorship Annual Conference in Washington, DC. on March 8-9, 1999.
- *"National Native American Breast Cancer Survivors Support Network"* for the Network for Cancer Control Research among American Indian and Alaska Native Populations, supported by the NCI, in Washington, DC on April 9-10, 1999.
- *"Native American Cancer Survivor: How the community can help"* at Rincon Reservation, CA on May 19, 1999.
- *"National Native American Cancer Survivors' Support Network"* at the Northwest Portland Area Indian Health Board in Reno, Nevada on July 15, 1999.
- *"National Native American Cancer Survivors' Support Network"* at CDC Challenges of Comprehensive Cancer Control in Atlanta, GA on September 9, 1999.
- *"National Native American Cancer Survivors' Support Network"* at the National Susan G. Komen Breast Cancer Foundation Grantee's Conference in Dallas, TX on October 4, 1999.
- *"National Native American Cancer Survivors' Support Network"* at American Public Health Association in Chicago, IL on November 8, 1999.

2000 Presentations: (Chronological Order for which information about the Network was included or highlighted)

- *"Cancer"*, to the Native Elder's Research Center (NERC), Resource Center for Minority Aging Research (RCMAR) at the University of Colorado Health Sciences Center, Denver, CO on January 9, 2000.
- *"National Native American Cancer Survivors' Support Network"* (co-presented with Terrie Restivo) at the 7th Biennial Symposium on Minorities and Medically Underserved Populations and Cancer in Washington, D.C. on February 12, 2000.
- *"National Native American Cancer Survivors' Support Network"* (co-presented with Alisa Gilbert) at the University of Oklahoma's Wellness and Women Conference in San Diego, CA on March 22, 2000.
- *"Native American Culturally Competent and Community Driven Research"* at the OHSU Native American Cancer Researchers' Training Program in March 23, 2000.
- *"Native American Health Issues, Lessons Learned from Community-based Interventions, and Overview of Native Cancer Projects"* at the University of North Carolina's Summer Public Health Research Videoconference on Minority Health in North Carolina on June 12, 2000.
- *"Native American Cancer Research and Community-Driven Interventions"* at the National Cancer Institute Research Fellows Training in Rockville, M.D. on August 1, 2000.

PERSONNEL RECEIVING PAY FORM THE RESEARCH EFFORT

| <i>Name</i> | <i>Role on Project</i> | <i>Native American?</i> |
|--|---|-------------------------|
| Linda Burhansstipanov, M.S.P.H., Dr.P.H. | PI | Yes |
| Richard E. Clark | Data Mgr | |
| Judy Hariton | Administrative Coordinator | |
| Mark Dignan, Ph.D. | Co-Investigator | |
| Alisa Gilbert | Network Coordinator, Survivor Advocate | Yes, Alaska Native |
| Khari LaMarca, M.P.H. | Survivor Advocate | Yes |
| Regina Grass, M.P.H. | Survivor Advocate | Yes |
| Patti King, LPN | Survivor Advocate | Yes |
| Elizabeth Stops | Survivor Advocate | Yes |
| James Hampton, M.D. | Consultant - Oncologist | Yes |
| Jennie Joe, Ph.D. | Consultant - Survivor | Yes |
| Judith S. Kaur, M.D. | Consultant - Oncologist | Yes |
| Linda Krebs, ON, Ph.D | Consultant | |